HEALTH CARE & HEALTH HABITS

The most important thing to do as an adult is to do everything you can to be healthy. This means eating the right foods, getting exercise, going to the doctor, and taking any medication that your doctor tells you to. This section is about things to think about as a person with Down Syndrome so you can be as healthy as possible.

Health

People who talk to their doctors and understand their own health care needs are likely to be healthier than those who don't. Learn to be an active participant in taking care of your health.

Learn about your health conditions. Do you know how to watch for the warning signs of problems? Do you know how to call your doctor to ask about a problem? Live your life by developing healthy habits: eat right, exercise, sleep and take care of your body.

You and your doctor need to talk to each other. When you were a young child, your parents probably did most of the talking for you. As you get older, you should try to do more and more of the talking yourself. Family and caregivers can help with communication with the doctor once you are an adult as long as you give them permission to do so.

The following topics are included in this section:

Down Syndrome & You (Canadian guide)
Family sheet – Transition & Health Care
How well do you know your health
Being Healthy – Think, Plan, Do
Stressors and Behavior problems
Nutrition
Exercise and staying fit
Sleep hygiene
Hygiene
Finding and Using Adult Health Care
Health Care Recommendations for Adults with Down Syndrome
Crisis assistance services
What is CYACC?
DisDat Tool
Self-Talk with Down Syndrome
Dementia in Down Syndrome
Adapting to Sleep Apnea

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Finding and Using Adult Health Care

As young people grow from childhood into adulthood, many will move from care by pediatricians into adult medicine provided by one of the three following specialties: internal medicine, medicine-pediatric or family medicine doctors.

So, how do you find a doctor who will meet your medical needs, that will be covered by your health plan, and who will give you the care you are looking for?

Before you start looking for a new doctor, think about **what you want**:

- Is where the office located important? Will you need help with transportation?
- Do you need an office that is wheelchair accessible or do you need other special assistance in the doctor's office?
- Are office hours convenient? How do you contact the doctor at other times? What hospital do you want to use, and is this doctor on the staff there?
- Do you want someone who will take time with you during an office visit or are you comfortable being seen by someone who is "good" in his or her field but perhaps does not have the best bedside manner?
- Is it important that this new doctor is knowledgeable about your special health care needs or do you think you can provide that information or connect the new doctor with those who could provide medical insight?

Ways to **look for a new doctor** include:

- Ask your current doctor
- Check out the doctor your parents or other family members see
- Call a family support group or adult disability agency and check around
- Ask adults who have health needs similar to yours for recommendations
- Refer to your health insurance company booklet of approved providers
- Ask a Vocational Rehabilitation or Independent Living Center counselor
- Find a university health center (sometimes there are research studies going on which offer free care)

Contact your local Medical Society, or the Family Practitioner or Internal Medicine Society either through the Yellow Pages or on their national websites.

It is important that you are comfortable talking with your new doctor and feel that he or she understands your concerns. The best time to see a new physician is when your health condition is stable so you aren't asking for crisis care while seeing if you can develop a working relationship.

Think about (and write down) **practice issues that are important to you**:

- Is the doctor knowledgeable about your health issues and/or willing to learn from you and from previous doctors?
- Do you like the communication style with the doctor and in the office?
- Are you satisfied with office practices and access during an emergency or in urgent situations?
- Do you have access to hospitals and specialists if you need them?

Doctors who like to care for adults may have a different medical style from doctors who like to care for children. Young adults seeking health care should prepare to become the managers of their own care with advice and consultation from the adult doctor. Young adults are encouraged to work on the following **healthcare self-management skills**:

- Ability and willingness to tell the doctor about your history, current symptoms, lifestyle, and self-care in just a few minutes (including carrying your own records and a summary of your medical history).
- Ability to ask questions about your condition and how it will affect your school, work, recreation, and social life.
- Ability to tell the doctor about your needs for education, technology, and accommodations and how your condition affects or might be affected by these.
- Willingness to follow medical recommendations that have been mutually developed by you and your doctor.
- More independence in following up with referrals and keeping all agencies informed.
- More involvement in keeping yourself well with diet, exercise and recreation, following medication, treatment and hygiene regimens, limiting risk-taking behaviors (such as drinking alcohol, smoking, taking non-prescription drugs, or unsafe sexual practices), and getting help when you feel angry, lonely, or sad for long periods.
- Being more aware of your physical and mental symptoms and health needs before you have a serious medical crisis and knowing when to inform your doctor.
- Developing a plan for action for when you need emergency care: when to consult with the doctor, what hospital to report to, what care you want and do not want, and naming someone who can let your wishes be known if you cannot (health care surrogate).
- Understanding how the health care benefits/insurance plan you have works for you: when to call for pre-approval, how to get reimbursements, what services are not covered, and how to file an appeal if you do not agree with decisions from the plan.
- Recognizing that as you become more capable in directing your care that you, not your parents, should make medical appointments, be the most knowledgeable about your health needs, know when to seek guidance in solving problems, and demonstrate that you are capable and competent and ready for adulthood!

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Adapted from the KY TEACH Project, KY Commission for children with special health care needs

HEALTH CARE RECOMMENDATIONS FOR ADULTS WITH DOWN SYNDROME

Patient Name: _____ DOB: _____ Height: _____

Health Guidance Assess the following at every visit	**Date of Service:**					
Obesity: Current BMI - BMI 25-29.9 = overweight, BMI >29.9 = obese						
Diet: low-calorie, high-fiber						
Physical activity: Goal 150 min moderate physical activity weekly + muscle strengthening twice weekly						
Tobacco Use: Avoid smoke exposure. Indicate Never/Former (stop date)/Current (amount)/Secondhand						
Alcohol Use: Adult use in moderation or as recommended. Never/current (amount)						
Street Drug/Prescription/Narcotic Use: Never/current (what, frequency)						
Monitor for behavior and mental health including depression and social isolation. Provide support and self-advocacy resources.						
Sexuality Education: Educate regarding self-touch, victimization, sexual expression.						
Disease-specific Health Education: Info related to current conditions						
Family and Parent Group Info: screen for family dynamic issues, caregiver respite / stress.						
Estate Planning						
Health Decision Making Support by guardianship, power of attorney, health care representative as appropriate						
Living Arrangements						
Community Activities for building self-worth and avoiding isolation – work, volunteer, socials.						

Immunizations

	Date of Service:
Influenza yearly	
Pneumococcal once < age 65 for high-risk (e.g. cardiac, lung disease), once > age 65	
Td/Tdap every 10 years or after 5 years if exposed	
HPV 3 dose series for females ages 9-26	
Hepatitis B if living/working in group setting	
Meningococcal if living/working in group setting	
Varicella 2 doses if no h/o disease	
Zoster once after age 60	

Screening and Tests

	Dates of service/Results:
Dental Examination every 6 months	
Thyroid function TSH, T4 yearly	
Auditory Testing every 2 years	
Ophthalmologic Exam every 2 years, looking especially for keratoconus, cataracts	
Heart Evaluation esp. for mitral prolapse or aortic regurgitation. Echo if suspected.[1]	
Clinical Evaluation for **Obstructive Sleep Apnea** Overnight oximetry if symptoms.	
Neurological Examination for atlantoaxial instability[2]	
Clinical Evaluation of **Functional Abilities**[3]	
Clinical Evaluation for **Dementia** and neurological eval for symptoms	
Clinical Evaluation for **Dysphagia/ Aspiration** symptoms at least yearly	
Clinical Evaluation for **Constipation** at least yearly. Maintain soft, easy stooling	
Clinical Evaluation for **Celiac Disease** with varied presentation –variety of GI symptoms, weight loss	
Lipid Profile at least every 5 years in women >45, men >35, if high risk >20.	
Colorectal Cancer Screening FOBT every 1-2 years, colonoscopy every 10 years if > 50, sooner if high risk	
Cervical Cancer pap smear at least every 3 years for sexually active women 21-65 years	
Clinical Breast Exam and Mammogram every 2 years for women >50, earlier for high risk, and up to age 74	
Testicular Exam consider yearly exam	
Prostate Exam Consider digital rectal exam and PSA test up to yearly starting at age 50, sooner if high risk	
Bone Density Consider for women >55 years. Women with DS generally have earlier menopause and lower bone density.	
Hypertension Measure at every medical encounter and at least annually	
Diabetes Screening FPG every 3 years for adults >45 and earlier/more frequently in high-risk groups	

(1) A history of congenital cardiac surgical repair increases risks for arrhythmias and congestive heart failure. Take history for evidence of arrhythmias regularly. These patients should have an echocardiogram (and cardiology follow-up) every 3 years.

(2) To assess spinal cord compression from atlantoaxial instability: assess gait, tone, Babinski responses, deep tendon reflexes, clonus. Also assess for neck pain, torticollis, gait disturbances, spasticity, weakness.

(3) A periodic assessment should be performed to assess functional capacity, involving occupational, physical, and speech therapists, as indicated. For loss of function, assess for thyroid function, depression, stress, Alzheimer's disease, sensory deficits, sleep apnea, osteoarthritis, and common medical conditions with an unusual presentation.

Crisis Assistance Services

Crisis Assistance Services provides specific supports to people with developmental disabilities with extreme behavioral or psychiatric issues.

Crisis Assistance Services include:

- 24/7/365 Telephone Crisis Support
- In-Home Technical Assistance
- Out-of-Home Short Term Residential
- Follow-Along Post Crisis Intervention

Call:

Northern Indiana: 866-416-4774
Central Indiana: 866-920-3272
Western and Southern Indiana: 866-416-4774

Psychiatric Consultation Service

Short-term psychiatric services are available at locations throughout Indiana for children and adults with developmental disabilities who:

- have extreme or challenging behavior or emotional issues;
- do not have a psychiatrist and may be in jeopardy, or
- have a psychiatrist who would like a consultation.

Call:

Central Indiana: 866-406-7134
Northern Indiana: 866-429-5290
Southern Indiana: 812-265-7493

What is CYACC?

Any youth with special health care needs from ages 11 to 22 and adults with developmental disabilities can come to the Center for Youth and Adults with Conditions of Childhood for a consult and transition support. CYACC is a multidisciplinary program whose goals are:

- To help youth with special health care needs prepare for their future adult lives.
- To help youth and families use the right services and community resources to achieve their goals.
- To work with primary care and subspecialty doctors, care coordinators, schools, community programs and services to improve transition and coordinate the care each youth needs.
- To provide medical consultation for adults with developmental disabilities and their families to help maintain their health and community activities.

We ask lots of questions and gather lots of information.

Together we make a **transition plan** that lists your personal goals along with suggested steps to meet those goals.

A **portable medical summary** is created to share your important health information with your current and future doctors.

At CYACC, we:

- Help find adult doctors to treat your health needs
- Help get adult health insurance once you grow out of your childhood plan
- Help find care coordinators who can assist you with getting services within the health system
- Help you think about your own self care
- Help you work well with your circle of support like your family and friends to make the decisions you need to reach your own goals
- Help you find the community resources that fit you and hopefully help meet your goals

Starting to plan early is a good idea. Anyone can refer a youth or young adult with special needs to CYACC. To ask about an appointment call 317-278-0061 or email cyacc@iupui.edu.

Disability Distress Assessment Tool

Individual's name:

DoB: **Gender:**

NHS No:

Your name:

Date completed:

Names of others who helped complete this form:

THE DISTRESS PASSPORT

Summary of signs and behaviours when content and when distressed

Appearance when CONTENT

Face Eyes

Tongue/jaw

Skin

Appearance when DISTRESSED

Face Eyes

Tongue/jaw

Skin

Vocal signs when CONTENT

Sounds

Speech

Vocal signs when DISTRESSED

Sounds

Speech

Habits and mannerisms when CONTENT

Habits

Mannerisms

Comfortable distance

Habits and mannerisms when DISTRESSED

Habits

Mannerisms

Comfortable distance

Posture & observations when CONTENT

Posture

Observations

Posture & observations when DISTRESSED

Posture

Observations

Known triggers of distress (write here any actions or situations that usually cause or worsen distress)

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Disability Distress Assessment Tool

Please take some time to think about and observe the individual under your care, especially their appearance and behaviours when they are both content and distressed. Use these pages to document these.

We have listed words in each section to help you to describe the signs and behaviours. You can circle the word or words that best describe the signs and behaviours when they are content and when they are distressed.

Your descriptions will provide you with a clearer picture of their 'language' of distress.

COMMUNICATION LEVEL *

This individual is unable to show likes or dislikes		Level 0
This individual is able to show that they like or don't like something		Level 1
This individual is able to show that they want more, or have had enough of something		Level 2
This individual is able to show anticipation for their like or dislike of something		Level 3
This individual is able to communicate detail, qualify, specify and/or indicate opinions		Level 4

* This is adapted from the Kidderminster Curriculum for Children and Adults with Profound Multiple Learning Difficulty (Jones, 1994, National Portage Association).

FACIAL SIGNS

Appearance

Information / instructions	Appearance when content	Appearance when distressed
(Ring) the words that best describe the facial appearance	Passive Laugh Smile Frown Grimace Startled Frightened Other:	Passive Laugh Smile Frown Grimace Startled Frightened Other:

Jaw movement

Information / instructions	Movement when content	Movement when distressed
(Ring) the words that best describe the jaw movement	Relaxed Drooping Grinding Biting Rigid Other:	Relaxed Drooping Grinding Biting Rigid Other:

Appearance of eyes

Information / instructions	Appearance when content	Appearance when distressed
(Ring) the words that best describe the appearance	Good eye contact Little eye contact Avoiding eye contact Closed eyes Staring Sleepy eyes 'Smiling' Winking Vacant Tears Dilated pupils Other:	Good eye contact Little eye contact Avoiding eye contact Closed eyes Staring Sleepy eyes 'Smiling' Winking Vacant Tears Dilated pupils Other:

SKIN APPEARANCE

Information / instructions	Appearance when content	Appearance when distressed
(Ring) the words that best describe the appearance	Normal Pale Flushed Sweaty Clammy Other:	Normal Pale Flushed Sweaty Clammy Other:

VOCAL SOUNDS (NB. The sounds that a person makes are not always linked to their feelings)

Information / instructions	Sounds when content	Sounds when distressed
Ring the words that best describe the sounds *Write down* commonly used sounds (write it as it sounds; 'tizz', 'eeiow', 'tetetetete'): …… …… ……	**Volume**: high medium low **Pitch**: high medium low **Duration:** short intermittent long **Description of sound / vocalisation**: Cry out Wail Scream laugh Groan / moan shout Gurgle Other:	**Volume:** high medium low **Pitch:** high medium low **Duration**: short intermittent long **Description of sound / vocalisation**: Cry out Wail Scream laugh Groan / moan shout Gurgle Other:

SPEECH

Information / instructions	Words when content	Words when distressed
Write down commonly used words and phrases. If no words are spoken, write NONE		
Ring the words which best describe the speech	Clear Stutters Slurred Unclear Muttering Fast Slow Loud Soft Whisper Other, eg. swearing	Clear Stutters Slurred Unclear Muttering Fast Slow Loud Soft Whisper Other, eg.swearing

HABITS & MANNERISMS

Information / instructions	Habits and mannerisms when content	Habits and mannerisms when distressed
Write down the habits or mannerisms, eg. "Rocks when sitting"		
Write down any special comforters, possessions or toys this person prefers.		
Please Ring the statements which best describe how comfortable this person is with other people being physically close by	Close with strangers Close only if known No one allowed close Withdraws if touched	Close with strangers Close only if known No one allowed close Withdraws if touched

BODY POSTURE

Information / instructions	Posture when content	Posture when distressed
Ring the words that best describe how this person sits and stands.	Normal Rigid Floppy Jerky Slumped Restless Tense Still Able to adjust position Leans to side Poor head control Way of walking: Normal / Abnormal Other:	Normal Rigid Floppy Jerky Slumped Restless Tense Still Able to adjust position Leans to side Poor head control Way of walking: Normal / Abnormal Other:

BODY OBSERVATIONS

Information / instructions	Observations when content	Observations when distressed
Describe the pulse, breathing, sleep, appetite and usual eating pattern, eg. eats very quickly, takes a long time with main course, eats puddings quickly, "picky".	Pulse: Breathing: Sleep: Appetite: Eating pattern:	Pulse: Breathing: Sleep: Appetite Eating pattern:

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Information and Instructions

DisDAT is

Intended to help identify distress cues in individuals who have severely limited communication.

Designed to describe an individual's usual content cues, thus enabling distress cues to be identified more clearly.

NOT a scoring tool. It documents what many carers have done instinctively for many years thus providing a record against which subtle changes can be compared.

Only the first step. Once distress has been identified the usual clinical decisions have to be made by professionals.

Meant to help you and the individual in your care. It gives you more confidence in the observation skills you already have, which in turn will give you more confidence when meeting other carers.

When to use DisDAT

When the team believes the individual is NOT distressed

The use of DisDAT is optional, but it can be used as a
- baseline assessment document
- transfer document for other teams

When the team believes the individual IS distressed

If DisDAT has already been completed it can be used to compare the present signs and behaviours with previous observations documented on DisDAT. It then serves as a baseline to monitor change.

If DisDAT has not been completed:

a) When the person is well known DisDAT can be used to document previous content signs and behaviours and compare these with the current observations

b) When the person is new to a carer, or the distress is new, DisDAT can be used document the present signs and behaviours to act a baseline to monitor change.

How to use DisDAT

1. **Observe the individual** when content and when distressed- document this on the inside pages. *Anyone* who cares for them can do this.
2. **Observe the context** in which distress is occurring.
3. **Use the clinical decision distress checklist** on this page to assess the possible cause.
4. **Treat or manage** the likeliest cause of the distress.
5. **The monitoring sheet** is a separate sheet, which may help if you want to see how the distress changes over time.
6. **The goal** is a reduction the number or severity of distress signs and behaviours.

Remember

- Most information comes from several carers together.
- The assessment form need not be completed all at once and may take a period of time.
- Reassessment is essential as the needs may change due to improvement or deterioration.
- Distress can be emotional, physical or psychological. What is a minor issue for one person can be major to another.
- If signs are recognised early then suitable interventions can be put in place to avoid a crisis.

Clinical decision distress checklist

Use this to help decide the cause of the distress

Is the new sign or behaviour?

- Repeated rapidly?

Consider pleuritic pain (in time with breathing)
Consider colic (comes and goes every few minutes)
Consider: repetitive movement due to boredom or fear.

- Associated with breathing?

Consider: infection, COPD, pleural effusion, tumour

- Worsened or precipitated by movement?

Consider: movement-related pains

- Related to eating?

Consider: food refusal through illness, fear or depression
Consider: food refusal because of swallowing problems
Consider: upper GI problems (oral hygiene, peptic ulcer, dyspepsia) or abdominal problems.

- Related to a specific situation?

Consider: frightening or painful situations.

- Associated with vomiting?

Consider: causes of nausea and vomiting.

- Associated with elimination (urine or faecal)?

Consider: urinary problems (infection, retention)
Consider: GI problems (diarrhoea, constipation)

- Present in a normally comfortable position or situation?

Consider: anxiety, depression, pains at rest (eg. colic, neuralgia), infection, nausea.

If you require any help or further information regarding DisDAT please contact:
Lynn Gibson 01670 394 260
Dorothy Matthews 01670 394 808
Dr. Claud Regnard 0191 285 0063 or e-mail on claudregnard@stoswaldsuk.org

For more information see
www.disdat.co.uk

Further reading

Regnard C, Matthews D, Gibson L, Clarke C, Watson B. Difficulties in identifying distress and its causes in people with severe communication problems. *International Journal of Palliative Nursing,* 2003, 9(3): 173-6.

Regnard C, Reynolds J, Watson B, Matthews D, Gibson L, Clarke C. Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). J Intellect Disability Res. 2007; **51(4)**: 277-292.

**Distress may be hidden,
but it is never silent**

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Down Syndrome News
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Draft Copy

"Self-Talk" in Adults with Down Syndrome

By Dennis McGuire, Ph.D., Brian A. Chicoine, M.D., and Elaine Greenbaum, Ph.D, 2005.

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Do you talk to yourself? We all do at different times and in various situations. At the Adult Down Syndrome Center of Advocate Lutheran General Hospital, we have heard repeatedly that adults with DS talk to themselves. Sometimes, the reports from parents and caregivers reflect deep concern that this behavior is "not normal" and symptomatic of severe psychological problems.

Preventing misinterpretation of self-talk as a sign of psychosis in adults with DS is a major motivation for this article. Too often, we believe, these conversations with self or imaginary companions have been equated with "hearing of voices and treated with anti-psychotic medications (such as Haldol®, Mellaril®, or Risperdal®). Since it is extremely difficult to evaluate the thought processes of adults with cognitive impairments and limited verbal skills, we urge a very cautious approach in interpreting and treating what seems to be a common and at times very helpful coping behavior for adults with DS.

The Adult DS Center was developed to address the health and psycho-social needs of adults with DS. Our records indicate that 81 percent of adults seen engage in conversations with themselves or imaginary companions.

Helpful Self-talk

Families and caregivers should understand that self-talk is not only "normal" but also useful. Self-talk plays an essential role in the cognitive development of children. Self-talk helps children coordinate their actions and thoughts and seems to be an important tool for learning new skills and higher level thinking. Three-year-old Suzy says to herself: "This red piece goes in the round hole." Then Suzy puts the red piece into the round hole of the puzzle.

We suspect that self-talk serves the same useful purpose of directing behavior for adults with DS. Consider the case of 22-year-old "Sam" (not his real name). His mother reported the following scene. She asks Sam to attend a family function on a Sunday afternoon. Sam's regular routine is to go to the movies on Sunday afternoons. Sam tells his mother he will not go with the family. Then the mother

asks Sam to think it over. Sam storms off to his room and slams the door. His mother overhears this dialogue:

"You should go with your family, Sam."

"But I want to go to the movies."

"Listen to your Mom!"

"But Sunday is my movie day."

"You can go next Sunday"

Sam's mother said he went to the family function, with the proviso that he could go to the movies the next Sunday. Sam may have been talking to an imaginary person or arguing with himself, but Sam clearly managed to cope with a situation not to his liking.

In children without identified learning problems, the use of self-talk is progressively internalized with age. Moreover, children with higher intellectual abilities seem to internalize their self-talk earlier. As self-talk is transformed into higher level thinking, it becomes abbreviated and the child begins to think rather than say the directions for his or her behavior. Thus, the intellectual and speech difficulties of adults with DS may contribute to the high prevalence of audible self-talk reported to us at the Center.

In general, the functions of self-talk among adults are not as well researched or understood. Common experience suggests that adults continue to talk to themselves out loud when they are alone and confronting new or difficult tasks. Though the occurrence may be much less frequent, the uses of the adult's self-talk seem consistent with the findings about children. Adults talk to themselves to direct their behavior and learn new skills. Because adults are more sensitive to social context and may not want to overhear these private conversations, their self-talk is observed less frequently.

Adults with DS show some sensitivity about the private nature of their self-talk. Like Sam in the example above, parents and caregivers report that self-talk often occurs behind closed doors or in settings where the adults think they are alone. Having trouble judging what is supposed to be private and what is considered “socially appropriate” also may contribute to the high prevalence of easily observable self-talk among the patients visiting the Center.

In the general population, self-talk among older persons is frequently notable and,

usually, easily accepted, just as it is with children. Among the elderly, social isolation and the increasing difficulty of most tasks of daily living may be important explanations for this greater frequency of self-talk. For adults with DS, these explanations also make sense. Adults with DS are at greater risk for social isolation and the challenges of daily living can be daunting.

Additionally, we have found that many adults with DS rely on self-talk to vent feelings such as sadness or frustration. They think out loud in order to process daily life events. This is because their speech or cognitive impairments inhibit communication. In fact, caregivers frequently note that the amount and intensity of the self-talk reflects the number and emotional intensity of the daily life events experienced by the individuals with DS.

For children, the elderly, and adults with DS, self-talk may be the only entertainment available when they are alone for long periods of time. For example, a mother reported that her daughter “Mary” spent hours in her room talking to her “fantasy friends” after they moved to a new neighborhood. Once Mary became more involved in social and work activities in her new neighborhood, she did not have the time or the need to talk to her imaginary friends as often.

Thus, that adults with DS use self-talk to cope, to vent, and to entertain themselves should not be viewed as a medical problem or mental illness. Indeed, self-talk may be one of the few tools available to adults with DS for asserting control over their lives and improving their sense of well-being.

When to Worry

The distinction between helpful and worrisome self-talk is not easy to cast in stone. In some cases, even very loud and threatening self-talk can be harmless. This use for self-talk by the adult with DS may not be that different from someone who rarely swears but screams out a four-letter word when hitting her thumb with a hammer. Such outbursts may simply be an immediate, almost reflexive outlet for some of life's frustrations.

Our best advice about when to worry is to listen carefully for changes in the frequency and context of the self-talk. When self-talk becomes dominated by remarks of self-disparagement and self-devaluation, intervention may be warranted. For example, it may be quite harmless when “Jenny” yells “I am a dummy,” once, right after her failure to bake a cake from scratch. However, if Jenny begins to tell herself over and over “I am a dummy and can't do anything right,” it may be time to worry and to do something.

A marked increase in the frequency and a change in tone of the self-talk also may

signal a developing problem. For example, a caregiver reported that “Bob” had begun to talk to himself more frequently and not just in his room at the group home. Bob seemed to lose interest in his housemates and spent more time in these conversations with himself. Bob talked to himself, sometimes loudly and in a threatening manner, at the bus stop, at the workshop, and at the group home. Bob was diagnosed as experiencing a severe form of depression. Over an extended period of time, Bob began to respond to an anti-depressant and to his participation in a counseling group.

In another case, “Jim” (like Bob) showed a dramatic increase in self-talk. Jim refused to go to his workshop and to participate in the social activities that he once enjoyed. It turned out that Jim's change in behavior was not due to depression. Instead, Jim's family and staff at his workshop discovered that Jim was being intimidated and harassed by a new co-worker. With the removal of the bully from his workshop, Jim gradually regained his sense of trust in the safety of the workshop. His self-talk and interest in participating in activities returned to earlier levels.

Further study of the content, context, tone, and frequency of the self-talk of adults with DS may provide more insight into their private inner worlds. What we have observed and heard from family and caregivers suggests that self-talk is an important coping tool and only rarely should it be considered a symptom of severe mental illness or psychosis. A dramatic change in self-talk may indicate a mental health or situational problem. Despite the odd or disturbing nature of the self-talk, our experience at the Center indicates that self-talk allows adults with DS to problem-solve, to vent their feelings, to entertain themselves, and to process the events of their daily lives.

Alzheimer's and Down Syndrome

Alzheimer's and Down Syndrome

print

Alzheimer's Disease, a degenerative neurological disorder characterized by progressive memory loss, personality changes and loss of functional motor capabilities, is far more common in individuals with Down syndrome than the general population. However, not all individuals with Down syndrome will develop Alzheimer's disease, and even those showing Alzheimer's-type symptoms may not have Alzheimer's disease since other conditions can mimic the symptoms.

How common is Alzheimer's disease in individuals with Down syndrome?

Estimates vary, but a reasonable conclusion is that 25 percent or more of individuals with Down syndrome over age 35 show clinical signs and symptoms of Alzheimer's-type dementia. The percentage increases with age. In the general population, Alzheimer's disease does not usually develop before age 50, and the highest incidence (in people over age 65) is between five and 10 percent. The incidence of Alzheimer's disease in the Down syndrome population is estimated to be three to five times greater than in the general population, and oftentimes, symptoms begin much earlier.

What are the symptoms of Alzheimer's disease?

Early symptoms include loss of memory and logical thinking, personality change, decline in daily living skills, new onset of seizures, changes in coordination and gait, and loss of continence in bladder and bowel habits.

How is a final diagnosis made?

Alzheimer's disease is difficult to diagnose. It is important to be certain Alzheimer's-type symptoms do not arise from other conditions, namely thyroid disorders, clinical depression, brain tumor, recurrent brain strokes, metabolic imbalances and various neurological conditions.

The diagnosis of Alzheimer's disease is made on the basis of clinical history, showing a slow, steady decrease in cognitive function and a variety of laboratory tests which provide contributory evidence, including electroencephalogram, brain stem auditory evoked response, computerized transaxial tomography and magnetic resonance imaging, among other tests and measurements.

Is there a baseline test that can be repeated at intervals to determine specific decrease in cognitive function?

Psychologists often use questionnaires answered by family members, companions or caretakers that

assist in the early detection of dementia. It is recommended that individuals with Down syndrome be tested at age 30 to provide a baseline reading, and periodically thereafter. If the tests show deterioration, further tests must be made to rule out conditions that present similar or overlapping symptoms.

What information has research yielded about a link between Alzheimer's disease and Down syndrome?

Current research investigating how certain genes on Chromosome 21 may predispose individuals with Down syndrome to Alzheimer's disease. A number of centers are testing therapies in Down syndrome that appear to benefit patients with Alzheimer's disease in the general population.

Alzheimer's and Down Syndrome Resource List

Organizations, Websites and Articles

Alzheimer's Association
225 North Michigan Avenue, Floor 17
Chicago, IL 60601
Telephone: 800-272-3900 (24-hour hotline)
Website: http://www.alz.org

Alzheimer's Disease International's fact sheet on dementia and intellectual disabilities:
http://www.alz.co.uk/adi/publications.html

Alzheimer's disease and people with mental retardation article:
http://www.thearc.org/netcommunity/document.doc

Developmental disabilities and Alzheimer's disease: What You Should Know
http://www.thearc.org à click "Publications"

Books on Alzheimer's Disease and Down Syndrome

Holland, A. "Down Syndrome and Dementia". In Dementia. London, UK: Oxford University Press (2000). http://www.oup.co.uk

Janicki, M. Dalton, A.J.P. Dementia, Aging, and Intellectual Disabilities: A Handbook. Brunner/Mazel Publisher (1999). Now Routledge Mental Health.

McGuire, D & Chicoine, B. Mental Wellness in Adults with Down Syndrome. Bethesda, MD: Woodbine House (2005). http://www.woodbinehouse.com

Prasher, V. P. Alzheimer's Disease and Dementia in Down Syndrome and Intellectual Disabilities. Radcliffe Publishing (2005). http://www.radcliffe-oxford.com

Obstructive Sleep Apnea Is Prevalent In Adults With Down Syndrome

ScienceDaily (Aug. 17, 2009) — A study in the Aug. 15 issue of the *Journal of Clinical Sleep Medicine* shows that adults with Down syndrome also frequently suffer from obstructive sleep apnea (OSA). However, complications of untreated OSA such as cardiovascular disease, daytime sleepiness and impaired cognitive functioning overlap with the signs of Down syndrome; therefore, OSA may not be detected.

Results indicate that 88% of adults in the study had at least moderate obstructive sleep apnea. Twelve of the 16 subjects with Down syndrome were obese, and there was a significant correlation between obesity and apnea.

It is well known that individuals with Down syndrome are at risk for OSA. "Patients with Down syndrome have a great deal of risk factors for OSA (based on their narrow midface, large tongue, floppy muscle tone, tendency towards being overweight, and thyroid disease)," said Carole Marcus, M.B.B.Ch., professor of pediatrics at the University of Pennsylvania and director of the Children's Hospital of Philadelphia Sleep Center. "However, the fact that almost all of the subjects studied had OSA was a much higher prevalence than we expected. It was surprising how severe the illness was, and how the OSA was unsuspected by their caregivers."

The authors suggest that obesity, a common and potentially treatable problem in Down syndrome, appears to play an important role in the problems of OSA in this population.

According to the American Academy of Sleep Medicine, OSA is a sleep-related breathing disorder that involves a decrease or complete halt in airflow despite an ongoing effort to breathe. It occurs when the muscles relax during sleep, causing soft tissue in the back of the throat to collapse and block the upper airway. This leads to partial reductions and complete pauses in breathing that can produce abrupt drops in blood oxygen saturation. Most people with OSA snore loudly and frequently, and they often experience excessive daytime sleepiness.

Using CPAP with Your Toddler (2 to 5 Years)

Getting started with continuous positive airway pressure (CPAP)

Sleep is an important part of staying healthy for children of all ages. About 3% of children have a sleep disturbance called obstructive sleep apnea. If your child has been prescribed a CPAP (continuous positive airway pressure) machine while sleeping, this handout offers tips to help you and your child adjust to it.

It's your job to help your child use CPAP during sleep. CPAP helps your child wake up rested and function well throughout the day. Using CPAP can become a normal part of your child's sleep routine and help keep your child healthy.

How is my toddler growing and developing?

Your toddler continues to grow and develop physically, mentally and emotionally. Toddlers usually can understand more than they can communicate. Children at this age begin developing language and verbal skills and their vocabulary grows rapidly each year. They have vivid imaginations and a limited understanding of cause and effect. They think very literally — a phrase like "You're driving me up the wall" is likely to be confusing and sound like nonsense to a child this age. Around 3½ years, children begin to understand the idea of good behavior and being rewarded in the future for what they do in the present (delayed gratification).

What might happen	Tips for CPAP use
Your toddler may refuse to put on the mask or pull off the mask repeatedly.	• Set up a consistent bedtime routine, incorporate CPAP into the routine and stick with it. Where appropriate, let your toddler help set the bedtime routine. Be consistent and firm about your toddler's CPAP use. If your toddler pulls off the mask, replace it on your toddler's face. • It is common when first using CPAP for the mask to be pulled off in the middle of the night. You can choose to check on your child in the middle of the night and replace the mask if it has come off. Hopefully, this will only be a problem for the first few weeks, and your child will become used to the mask and wear it through the night. Your child will begin to understand that if the mask comes off, it will be replaced. • Establish a transition time before bedtime. Let your child know how many minutes remain before it's time to begin the bedtime routine. Do not allow extra minutes or give your child less time than what you said. • Keep the bedtime routine simple. For example, a child's bedtime routine could include changing into pajamas, brushing teeth, reading a bedtime story and putting on the CPAP mask. Shift other activities (such as picking out clothes for the next day) to the next morning or other times of the day.

(Continued on back)

What might happen	Tips for CPAP use
Your toddler may resist using CPAP by throwing temper tantrums or crying. Your toddler may also regress in behavior as a sign of frustration or dissatisfaction. Your toddler may not be able to effectively communicate their feelings to you and may behave negatively or respond aggressively toward you, the bedtime routine or the CPAP machine and mask.	• Don't take this phase too personally — this is a normal stage. Your toddler's "No" may be an expression of dissatisfaction or a way for the child to try to gain control of the situation or push limits. Your toddler needs you to stay consistent during this time. • Try giving your toddler extra choices around CPAP, such as, "Do you want to push the button to start the CPAP machine or do you want Mom or Dad to do it?" Or, "Do you want to read your bedtime story before or after putting on your mask?" Do not give your child a choice if there is not a choice to be made, such as in asking, "Do you want to wear your CPAP mask or not?" • Stop aggressive action right away. Teach your child healthy ways to verbalize feelings. Provide alternative methods for aggressive behavior and give positive feedback for non-aggressive behavior. Avoid fighting or getting into a power struggle with your child over wearing CPAP. Make using CPAP fun. Make it a game or activity, and continue to make it part of the bedtime routine.
Your toddler may ask a lot of questions or ask the same questions over and over.	• Be prepared to answer your toddler's questions — repetition is one way children at this age learn. Your toddler may need to repeat an activity many times before adjusting to this new routine and activity.
Your toddler may like to play with the mask, but refuse to wear it at bedtime or naptime.	• Encourage your toddler's natural curiosity and positive play with the mask. Use that as a first step in getting your child used to the mask. (See the desensitization tips below.)
It is common for caregivers to be concerned about their toddler's reactions to CPAP.	• Talk with your sleep clinic or home-care company about your concerns. • If your toddler has special health-care needs, stay in contact with your specialty clinics. The clinic staff may be able to offer assistance in helping your child adjust to wearing a mask and using CPAP. • Attend CPAP support group meetings.

Desensitization tips for your toddler

1. Practice relaxation or breathing techniques and breathing through the nose. This could be incorporated into part of the bedtime routine, or could be done in the car or anywhere.
2. Throughout the process, talk to your toddler about CPAP while putting on the mask or getting ready for sleep. Talk about why they need to wear the mask and what it does. Explain the parts of the machine.
3. If your machine or humidifier makes noise or hums, turn it on upon walking in the room so your toddler gets used to the noise.
4. Let your toddler hold or play with the mask.
5. Try one or more of these ideas:
   - Put the mask and headgear on a teddy bear or doll. You may wish to give your toddler a doll or stuffed animal that wears a mask. (Be sure the mask is securely attached to the toy so that it is not a choking hazard.)

(Continued on next page)

- Get masks or silly noses for family members to wear, such as toy animal noses, clown noses or a small plastic cup. Wear a mask or silly nose while holding your toddler or during the bedtime routine.
- Give your toddler jobs related to CPAP that they can help with, such as holding the mask while you put on the straps, turning on the machine or helping you clean the mask.
- Give your toddler a doll to draw on. (Contact the Child Life Department at Children's at (206) 987-3285.)
- Read a book about firefighters with masks, color in a coloring book that features masks or create a puppet show about using CPAP. Encourage your toddler to draw a mask on pictures of children or animals in coloring books.

6. Gradually move the mask closer and closer to your toddler's face. Place the mask on your toddler's face for 2 minutes and gradually increase to longer periods, with the tubing disconnected from the machine. If your toddler watches TV, start with a 60-second commercial and work up to a 15- to 30-minute cartoon. Your toddler may find it comforting to be held during this process.
7. With the tubing connected and the machine turned on, let your toddler play with the airflow. Your toddler might speak into the airflow — pretend the airflow is a hair dryer or blow air in the face.
8. Once your child can comfortably wear the mask for 30 minutes with the tubing disconnected from the CPAP machine, repeat steps 1 through 3 with the tubing connected to the machine and the machine turned on. Do this until your child can wear the mask with the machine turned on. Hopefully, your toddler will be relaxed enough with the machine to be able to fall asleep with it on at bedtime.
   - Use positive reinforcements or rewards for any attempts your toddler makes. Use favorite video games, TV shows, toys, books and/or music to help distract your child from focusing on the new feelings of having the mask on. There is not a set length for the desensitization process, but it is important to work with your child every day. It is also helpful to work with your child on this process at least a few times each day, rather than only at night. Being able to wear the mask during the day while awake means that your child will be more likely to wear it at bedtime.
   - During the day, work toward wearing the mask for longer periods by rewarding your child with something they like. Try placing the mask on your child while watching a favorite video. If your child pulls the mask off, then turn off the video. Continue this until your child tolerates wearing the mask with the machine on.
9. Have your toddler wear the headgear and mask with the CPAP machine turned on to fall asleep when tired, either for a nap or at night. Once your child can fall asleep with the machine on and sleeps for most of the night with it on, you have successfully completed the desensitization plan. Congratulations!

Call your home-care company with any questions or concerns about the mask, mask fit or the machine. For any concerns about your toddler's health or breathing related to CPAP, call the Children's Hospital Sleep Disorders Center at (206) 987-8938.

Sleep disorders resource

Jodi Mindell, *Sleeping Through the Night: How Infants, Toddlers and Their Parents Can Get a Good Night's Sleep.*

TO LEARN MORE

- **Sleep Disorders Center (206) 987-8938**
- **Your Child's Health-Care Provider**

Children's will make this information available in alternate formats upon request. Please call Marketing Communications at (206) 987-5205.

This handout has been reviewed by clinical staff at Children's Hospital. However, your child's needs are unique. Before you act or rely upon this information, please talk with your child's health-care provider.

Children's
Hospital & Regional Medical Center
www.seattlechildrens.org

5/07
(NPG)
PE658

RAISE YOUR VOICE

You are a target! Right now tobacco companies are using advertising and marketing practices to target you.

How? They place ads in magazines you read that make smoking look cool and mature. They've even created mythic "heroes" like a cowboy or a cool camel to make smoking look hip. Why? They need you to replace the 27 Hoosier customers their products kill everyday.

You don't have to take their targeting quietly. Have your say and join VOICE.

VOICE is Indiana's youth movement against the tobacco industry, aka Big Tobacco.

We're teens from all over the state, just like you, and we've had enough of Big Tobacco so we're fighting back.

Use your VOICE and join us as we target the tobacco industry with our secret weapon... The TRUTH.

Stay Informed!
Sign up for more information and updates from VOICE!

at www.voice.tv

Secondhand Tobacco Smoke and the Health of Your Family

Make your home smoke-free.
Secondhand smoke is the smoke that comes from a cigarette or other tobacco that *someone other than you* is smoking.

Secondhand Smoke is Dangerous

Everyone knows that smoking is bad for smokers, but did you know—

- Breathing smoke from someone else's cigarette, pipe, or cigar can make you and your children sick.
- Smoking inside a home or car is more dangerous because smoke gets trapped inside—even fans and open windows don't help.
- Children who live in homes where people smoke get sick more often with coughs, breathing problems such as asthma, and ear infections.
- Secondhand smoke is also linked to Sudden Infant Death Syndrome (SIDS).
- Secondhand smoke can cause lung cancer in adults and is also bad for the heart.

Protect Your Family

- Make your home and car smoke-free.
- Family, friends, and visitors should never smoke inside.
- If you smoke, smoke only outside.
- Ask your doctor for ways to help you stop smoking.

Remember

Keeping a smoke-free home can help improve your health, the health of your children, and your community.

www.epa.gov/smokefree

Smoke-Free Homes Program
Programa de Hogares Libres de Humo

EPA
United States Environmental Protection Agency

EPA 402-F-06-004
March 2006

El humo de tabaco en el medio ambiente y la salud de su familia

Mantenga su hogar libre del humo de tabaco. El humo de tabaco en el medio ambiente es el humo que sale de un cigarrillo o de un tabaco que está fumando otra persona.

El humo de tabaco en el medio ambiente es peligroso

Todo el mundo sabe que fumar es malo para los fumadores, pero sabía usted que—

- Respirar el humo que sale del cigarrillo, de la pipa o del puro de otra persona pueden enfermarlos a usted y a sus hijos.
- Fumar en el hogar o en el automóvil es peligroso porque el humo se queda dentro—ni siquiera los ventiladores o las ventanas ayudan.
- Los niños que viven en casas donde las personas fuman se enferman con mayor frecuencia. Los mismos sufren de infecciones de oído y de problemas respiratorios como el asma y la tos.
- El humo de tabaco en el medio ambiente también está vinculado con el Síndrome de Muerte Súbita del Infante (SIDS por sus siglas en inglés).
- El humo de tabaco en el medio ambiente puede causar cáncer de los pulmones en adultos y es también perjudicial al corazón.

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Proteja a su familia

- Matenga su hogar y automóvil libres del humo de tabaco.
- La familia, las amistades y las visitas nunca deben fumar dentro de su hogar.
- Si usted fuma, fume afuera solamente.
- Pregúntele a su doctor com puede dejar de fumar.

Recuerde

Mantener un hogar libre del humo de tabaco puede mejorar su salud, la salud de sus hijos y la de su comunidad.

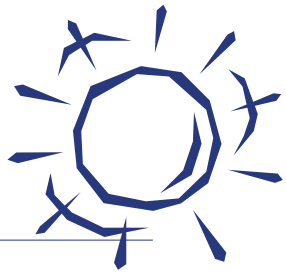
www.epa.gov/smokefree

Smoke-Free Homes Program
Programa de Hogares Libres de Humo

EPA United States Environmental Protection Agency

TRANSITION

HEALTH CARE



Family Sheet

Parents of children with special health care needs and disabilities need to plan, connect, advocate and find information on behalf of their child. Planning ahead is very important and makes a difference.

This fact sheet on health care transition explains important issues and lists practical steps that should be addressed in adolescence. The fact sheet discusses two aspects of health care transition. The first aspect is the need for increased responsibility by the adolescent for his/her own health care. The second is the need for families to plan for transfer of care from the pediatric provider to the adult provider.

Read the sheet and refer to it every now and then as you travel through the transition process with your adolescent.

- Begin by age 14 but plan over a period of time. Make a plan that is specific to your adolescent and his/ her special health care needs.
- If your adolescent has a special health care need or disability significant enough to interfere with his/ her ability to make financial and medical decisions, you will need to file a petition to the court six months before your adolescent turns 18 to maintain guardianship or to initiate conservatorship.
- Ask the provider how and when age-appropriate information will be shared with your adolescent about: his/ her disability or chronic illness, sexuality, preparing for parenthood, genetic counseling, vocational awareness, work opportunities and leisure time.
- Suggest to the provider that he/ she meet privately with your adolescent to discuss topics such as physical, emotional and sexual development, relationships and friendships, sexuality, alcohol, drug and tobacco use, and family issues.
- Ask the provider who on his/ her staff can assist you in care coordination.
- Ask the primary care provider or nurse for help in identifying others such as school nurses and personal care attendants who can help manage your adolescent's care.
- Talk to your adolescent about his/ her condition and/ or disability in a way that he/ she can understand. If your adolescent has developmental disabilities, work with his/ her primary care provider to choose the key points and figure out how to make them clear.
- Help your adolescent understand the importance of the medication he/ she takes.

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- Encourage your adolescent to make his/ her own health care appointments.
- Encourage your adolescent to prepare for doctor visits by writing down questions in advance. He/ she should also keep his/ her own health notes and records.
- Begin teaching your adolescent about his/ her insurance coverage.
- Discuss with the primary care provider when you should consider transferring your adolescent's care to an adult provider.
- If you decide that you should work towards a transfer of care, work with your adolescent's primary care provider to find appropriate adult providers.
- Talk to other families and young adults with similar special health care needs and disabilities to help you identify an appropriate adult health care provider for your adolescent.
- Schedule an interview visit with possible adult providers before transferring your adolescent's care. If possible, encourage your adolescent to call and schedule the visit.
- Visit with each provider to determine if he/ she is a good match for your adolescent.
- Ask your primary provider to transfer your adolescent's medical records prior to transfer of health care to the adult provider.

For more information...

Family TIES

Family TIES (Together In Enhancing Support) of Massachusetts is a statewide information and parent-to-parent support project for families of children with special needs and chronic illness.

Massachusetts Department of Public Health
Southeast Regional Office
109 Rhode Island Road
Lakeville, MA 02347
800-905-TIES (in-state)
www.massfamilyties.org

Exceptional Parent 2000 Annual Resource Guide

A resource guide providing information, support, ideas, encouragement and outreach for parents and families of children with disabilities and the professionals who work with them.

555 Kinderkamack Road
Oradell, NJ 07649-1517
201-634-6550
www.eparent.com

Produced by the Institute for Community Inclusion at Children's Hospital, Boston, as part of the Massachusetts Initiative for Youth with Disabilities, a project of the Massachusetts Department of Public Health. Supported in part by project # HO1MC00006 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

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How Well Do You Know Your Health?

1. What is your medical condition? Could you explain what it means to someone else?

Describe_____
_____
_____
_____
_____

2. When did you last receive education about your condition?_____
_____

3. How does your diagnosis affect your daily activities?

Describe_____
_____
_____
_____
_____

4. What are your "warning signs" that you need to see a doctor?

Describe_____
_____
_____
_____
_____

5. Under what circumstances would you call 911?

Describe_____
_____
_____
_____

6. Does your medical condition require any special treatment plan?

Describe_____
_____
_____
_____
_____

7. Do you follow a special diet?

Describe_____
_____
_____

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8. Do you use any medical equipment, orthotics, or prosthetics? If so, what and why? _____
_____

9. Do you know how to tell if your equipment is working correctly and what to do if it is not working correctly? _____
_____

10. What medications do you use?

Name? _____
Reason?_____
Dosage?_____
Time?_____
Potential side effects?_____

Name? _____
Reason?_____
Dosage?_____
Time?_____
Potential side effects?_____

Name? _____
Reason?_____
Dosage?_____
Time?_____
Potential side effects?_____

Name? _____
Reason?_____
Dosage?_____
Time?_____
Potential side effects?_____

Name? _____
Reason?_____
Dosage?_____
Time?_____
Potential side effects?_____

Name? _____
Reason?_____
Dosage?_____
Time?_____
Potential side effects?_____

11. What do you do if you miss a dose?_____
_____
_____

12. What pharmacy do you use? (Name & Phone)
_____

13. Have you ever called the pharmacy yourself for a refill?_____

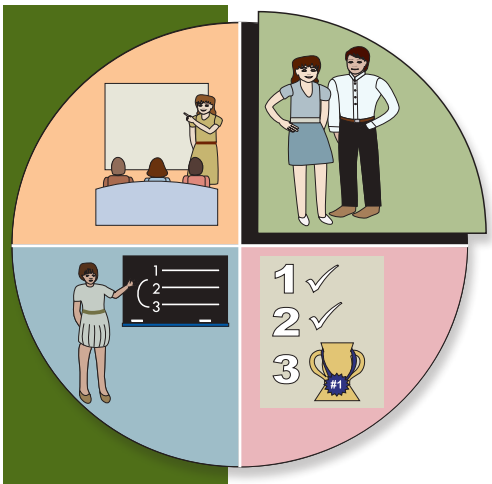
14. Who is your Primary Care Physician/Doctor? (Name, Address, & Phone)
_____
_____
_____
_____

15. What types of specialists do you see? (Specialty, Name, Address & Phone)
_____
_____
_____
_____
_____

16. How long will you continue on the same health insurance plan?
_____

17. Have you ever made yourself an appointment for a doctor visit?_____

18. What do you do to prepare for an appointment with your doctor?
_____
_____
_____
_____
_____



TAKING CARE OF YOURSELF

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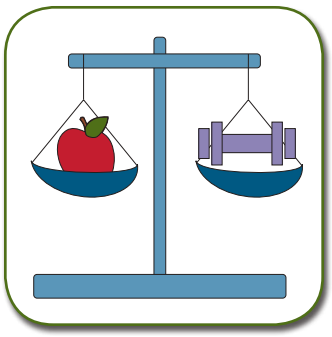
Being Healthy



THINK

Set the Goal

Think about how to be healthy so you are active and doing more things you want.

PLAN

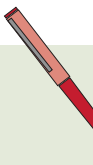
Take the Steps

Create a way to eat better food and get exercise.

DO

Make it Happen

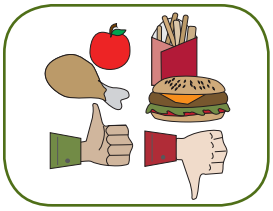
Make good food choices, do safe exercises and keep track of your successes.



NAME

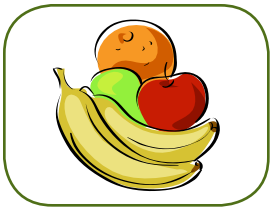
Department of Developmental Services, Office of Human Rights & Advocacy Services
1600 9th Street, Room 240, Sacramento, California 95814 (916) 654-1888 www.dds.ca.gov

Nyron's Story



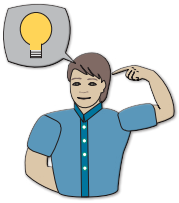
THINK: Nyron wanted to be healthy and do many things in his community. He wanted more energy and be in charge of himself. Nyron knew good eating and watching his sugar and cholesterol helps. He also wanted new ideas from his life coach and doctor about being healthier.

PLAN: Nyron decided what healthy foods to eat and what to stay away from. He thought about what exercises he could do safely. Nyron knew keeping track would help remind him. He got help making a chart to show his blood sugar and cholesterol. Nyron asked for support from his doctor and life coach so he could monitor his success.



DO: Nyon started eating healthy foods. His exercises built strength in his body. He felt better and lost weight. Nyon also watched his blood sugar and cholesterol levels carefully. He got stronger and felt in more control of his health. He began to show others how to improve their health.

Setting the Goal



THINK

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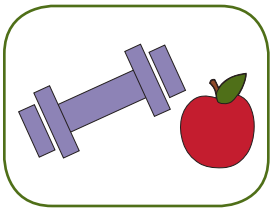
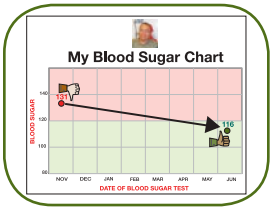


My health: How do I want to feel?

Being healthy, I can do these activities:



My healthy living goal is:

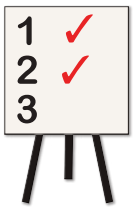
New choices I can make:

☐ Better food _____

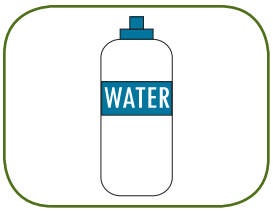
☐ New exercises I can try

_____

Taking the Next Steps

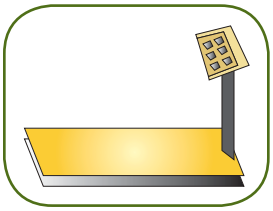


PLAN



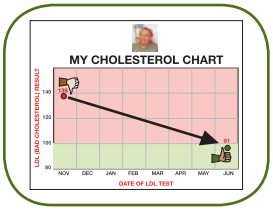
Better food choices:

- ☐ Eat more _____
- ☐ Eat less _____
- ☐ Drink more _____
- ☐ Drink less _____



Exercises I can do:

1. _____
2. _____



Being healthy in other ways:

1. _____
2. _____

What do I need to learn?

- ☐ Thinking positive.
- ☐ Being Patient.
- ☐ Listening before acting.
- ☐ Accepting advice.
- ☐ Being kind to myself.
- ☐ Speaking my mind.

Making It Happen

DO

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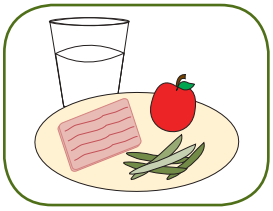
I will start my plan on:

Date

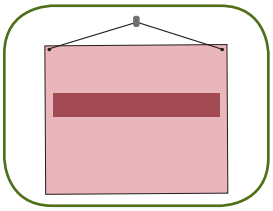
My food choices:



☐ Eat less ☐ Drink less

☐ Eat more ☐ Drink more

My exercise schedule:



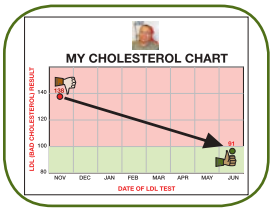
☐ Exercise #1 _____

Days _____ Time _____

☐ Exercise #2 _____

Days _____ Time _____

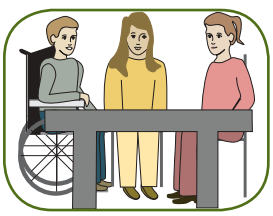
Make a chart to keep track of:



☐ Food ☐ Exercises

☐ Blood sugar ☐ Cholesterol

I will get support from:



☐ Friend ☐ Family ☐ Support Person

Name: _____

Methods to address stressors and behavioral problems

1. Ask for his/her explanation – use words, pictures, drawings
2. Attempt to look at situation from the person with disability's perspective
3. Anticipate and observe behaviors and emotions
4. Seek means to allow expression of emotions
5. Allow privacy for self talk
6. Substitute positive phrases for repetitive negative self-talk – "turn the channel"
7. Seek opportunities and activities to divert and occupy attention
8. Ignore negative behaviors or isolate during negative behaviors
9. Use behavior chart or calendar to measure good performance
10. Direct activities toward abilities
11. Promote positive view of self and special needs – find recreation and social activities, work with others in nursing home, rehab facility, etc.
12. Redirect unacceptable behaviors to one which are more acceptable
13. Develop social contacts
14. Create structure and consistent patterns when possible
15. Separate (at least temporarily) from situation or person provoking reaction
16. Prepare for changes – explain, review, give a warning
17. Use prompts and reminders (especially visual means)– pictures, calendars, clocks
18. Use self- photos or videos to remodel behaviors or habits
19. Break difficult task into smaller steps
20. Prevent confusion due to literal interpretations – i.e. morning and mourning
21. Redirect from negative memories to remind of good memories
22. Practice calming activities – deep breathing, exercise, warm bath, fishing, play cards, etc.
23. Consider avoiding giving information that is unnecessary
24. Art, music, sensory integration therapy

NUTRITION

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1. **Balance the types of food you eat**
2. **Eat Plenty of Fruits & Veggies**
3. **Drink Calorie-free drinks**
4. **Watch your portion sizes**
5. **Eat 3 meals and 2 snacks per day**
6. **Drink A LOT of water**

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7. **Stay away from fatty foods**

Good Ways to Exercise and Stay Fit*

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1. Go For a Walk with a friend or pet
2. Take a Swim
3. Ride a Bike – in place or outside
4. Walk Around the Mall
5. Go Bowling with Friends
6. Lift Weights
7. DANCE!
8. Join a Sports Team

Don't Forget to Drink Lots of Water and Eat Healthy Snacks Before, During & After Your Workout!

* Prior to starting an exercise program, you should be sure to have a physical exam and health screening completed by your doctor.

SLEEP HYGIENE

If you have trouble getting the sleep you need, work shifts, or simply cannot seem to find the time for sleep, then "sleep hygiene" is a practice that you need to work on more than others.

- Go to bed only when sleepy. Try a relaxing bedtime routine (e.g., soaking in a bath).
- Establish a good sleep environment with limited distractions (noise, light, temperature).
- Avoid foods, beverages, and medications that may contain stimulants.
- Avoid alcohol and nicotine before going to sleep.
- Consume less or no caffeine.
- Exercise regularly, but do so around midday or early afternoon. Over-training or exercising too much is not advisable.
- Try behavioral / relaxation techniques to assist with physical and mental relaxation.
- Avoid naps in late afternoon and evening.
- Avoid heavy meals close to bedtime.
- Avoid fluids before going to sleep.
- Use the bed only for sleep and intimacy (Do not eat, read or watch TV in bed!).
- Establish a regular wake time schedule.
- If you lie in bed for 20-30 minutes, and can not fall asleep, get up, do a quiet activity out of bed, then return to bed again when you feel ready to try to sleep.

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RELAXATION TECHNIQUES

Your breathing pattern changes when you are tense and anxious. You breathe faster, your muscles use more oxygen, your breathing muscles tighten, and your airways narrow.

Practicing progressive relaxation helps relieve this tension and anxiety that accompanies your breathlessness. By learning to relax your mind and body you will feel better and decrease the amount of oxygen the muscles use. Most people cannot relax at will.

You need to learn how to relax. This skill allows you to gain control over stress and tension. Relaxation takes time and daily practice. Progressive relaxation will help you identify when you are becoming tense and allow you to relax any part of your body.

TO PRACTICE:
1 . Find a quiet peaceful place. Lie down on a comfortable surface and place a pillow under your head, arms, and knees.
2. Take in a slow relaxed breath. Breathe out slowly through your mouth. Let your body relax. Take 5-6 slow deep breaths in this manner. Think to yourself; **Calm in, Tension out**.
3. Now inhale. Tighten ankles and toes. Hold for a count of 5. Exhale and release slowly. Repeat 3 times.
4. Inhale. Tense calf, knee, and thigh muscles. Hold for a count of 5. Exhale and release slowly.
5. Inhale. Tense your abdominal muscles. Hold for a count of 5. Exhale and release slowly.
6. Clench your fist, tighten finger muscles and arm muscles. Hold for a count of 5. Exhale and relax.
7. Tighten your shoulders. Hold for a count of 5. Relax.
8. Tighten your face muscles. Clench your jaw, close eyelids tight, wrinkle your forehead. Hold for a count of 5. Relax.

Now just breathe. Relax every muscle. Start at your feet and gradually feel yourself relax each part of your body progressively from toes, to feet, to calves, to thighs, to hips, to abdomen, to chest, to fingers, to hands, to forearms, to upper arms/shoulders, to neck. Feel a sense of warmth and heaviness. Let yourself float.

Think of nothing except your breath flowing in and out. Lie still and enjoy the feeling of relaxation until you are ready to get up. Take a slow relaxed breath in, - exhale slowly through your mouth. Open your eyes, wiggle your feet. Move slowly when ready to sit up.

Do not RUSH.

QUICK RELAXATION

When you feel angry, nervousness, tense, or panicky.
1st - Close your eyes. Take a slow breath in.
2nd - Breathe out slowly, using Pursed Lip Breathing.
3rd - As you breathe out, let your shoulders drop a little and let your jaw drop - just enough so your teeth aren't touching.
4th - Tell yourself 'Stay calm and relax'.

The Thief of Sleep

Sounding the Alarm About Sleep Apnea

If you were at the doctor's office and suddenly stopped breathing for 20 seconds, they'd call an ambulance. During sleep, the more than 12 million Americans estimated to have obstructive sleep apnea may stop breathing 10 or more times an hour. When sleep is regularly disrupted throughout the night, the consequences can be dire, from dangerously sleepy driving to higher risks of diabetes and heart disease.

Sleep apnea, or sleep disordered breathing, brings repetitive periods of difficulty breathing and sleeping. According to Dr. Michael Twery, director of the National Center on Sleep Disorders Research at NIH's National Heart, Lung and Blood Institute, sleep apnea is often caused by a temporary obstruction to the airway opening at the back of the mouth. In children, it could be large tonsils; in adults, the tongue. Or it could stem from weight gain, as the airway passage narrows because of thickened fat pads. The muscles that normally keep the airway stiff and open while awake may relax during sleep, causing the airway to narrow or even close.

For people with a less common condition called central sleep apnea, the brain, for unknown reasons, occasionally fails to send signals to the muscles telling them to breathe.

Whatever the cause, when your breathing stops or becomes very shallow, the oxygen level in your blood goes down. Your brain senses an emergency and takes action to wake you up, doing whatever it takes to get air into your lungs and restore your breathing.

Trying to force air past an airway obstruction can cause loud snoring. In fact, one of the most common ways people discover they have sleep apnea is that their bed partner complains about the noise. Some people may also gasp for air. Most disturbing, however, may be the silence when there is no breathing during the apnea.

Anyone—including children—can have sleep apnea. If someone in your family has sleep apnea, you're more likely to develop it than someone without a family history of the condition. It's more common in African Americans, Hispanics and Pacific Islanders than in Caucasians. The reasons for these differences are unknown, and NIH is currently funding studies to understand why.

See your doctor if you suspect you have sleep apnea. Treatment includes making lifestyle changes, such as sleeping on your side instead of your back and losing weight if you are overweight. These might be enough if your sleep apnea is mild. For adults with moderate or severe sleep apnea, continuous positive airway pressure (CPAP) is the most common treatment. For CPAP, you wear a mask over your nose or mouth during sleep that blows air into your throat at a pressure level just high enough to prevent airway obstruction. Other treatments are also available.

You might have to try different treatments or methods for a time, but remember that sleep apnea is a treatable condition. Your doctor can recommend which treatments may help you after determining the cause of your apnea. ■

Wise Choices

Signs and Symptoms of Sleep Apnea

The most common signs of sleep apnea are:

- Loud, chronic snoring
- Choking or gasping during sleep
- Fighting sleepiness during the day when you thought you'd gotten enough sleep the night before

Others signs may include:

- Morning headaches
- Memory or learning problems
- Feeling irritable
- Not being able to concentrate on your work
- Mood swings or personality changes; perhaps feeling depressed
- Dry throat when you wake up

If you or someone close to you notices these symptoms, discuss them with your doctor. There are several effective treatments for sleep apnea.

Web Sites

- **www.nhlbi.nih.gov/health/dci/Diseases/SleepApnea/SleepApnea_WhatIs.html**
- **www.ninds.nih.gov/disorders/sleep_apnea/sleep_apnea.htm**

HYGIENE FOR HEALTH

Personal hygiene is essential for your health, for your interactions with other people and for getting respect in the work place.

Hand Washing

- Wash your hands regularly to keep from spreading infections and dirt. Wash your hands before eating. Wash your hands extra when you have a cold.

Brush Your Teeth Twice a Day

- Brush your teeth twice a day for healthy teeth and fresh breath. Don't rush when you brush. Spend a good two minutes brushing all your teeth surfaces.

Shower Daily

- Whether you feel like you need it or not, a shower is a great thing to do every day. Even if you are not able to smell your body odor, you need to shower regularly, at least every other day. Some people prefer to take their shower in the morning and others in the evening, either choice is fine.

Wear Clean Clothes

- Make sure you wash your clothes after you wear them a couple of times. Some people even need to wash their clothes after one wear if they were very active or sweaty.

Keep Nails Clean and Cut

- When you wash your hands, learn how to remove dirt from underneath your nails. Some people use a nail file and others use a small brush. Keep nails cut neatly to prevent infections or injury.

Proper Cleaning after Toileting

- Take care to clean up after using the bathroom. Avoid splashing on your clothes and the restroom. Use toilet tissue or cleansing pads to wipe yourself clean as needed. Always wash your hands after using the toilet.